Second Wind NEWSLETTER

September 2004

PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help, and general information for those with chronic respiratory disease through education, research, and information. This publication is one of the ways we do that. The Second Wind is not intended to be used for, nor relied upon, as specific advice in any given case. Prior to initiating or changing any course of treatment based on the information you find here, it is essential that you consult with your physician. We hope you find this newsletter of interest and of help.

Key Words: Adventures of an Oxy-phile; Pulling the Plug on Research Funding: What it Means to the Victims of Chronic Obstructive Pulmonary Disease by M.F. Bowen, Ph.D; COPD/Alpha 1 Day

Folks, have you ever had a hard drive on your computer crash? It is *disaster* with a capital D! Now, smart people have a backup. Really smart people have 2 backups. Really, really, really *unlucky* people have all of *those* corrupted too! And that is w hat happened to your poor editor. Data has been reproduced as w ell as possible since some things fortunately had a *3rd* backup, but it's spotty friends, it's spotty. If information or your name doesn't get properly credited let us know ! We'll attend to it immediately.

We wish we could blame the telephone number error for Dr. Petty's latest book as being computer caused but evidence points to human error. **Adventures of an Oxy-phile** can be obtained from the AARC (American Association of Respiratory Care), 9425 N. Mac Arthur Blvd., Irving, TX 75063. **The correct phone number is 972-243-2272.** Note that the first number is a **9,** not 8! We got lots of calls from nice, understanding people. "Adventures" seems to be going like hot cakes with lots of positive feedback about it coming in via email or phone! Try the new number again today and get your own copy.

Charlotte and Wm. Zilm, Emily & Hans Hansen, Mary Ellen & Joseph Weger, Hilda Sw anson, Philip Whitting and Joy Bresen w ere among those w ho joined Dr Petty as **"IndependenceDonors". Hal Lichterman** joined the Independence Donors but, in honor of Dr. Petty, w ent above and far beyond the original request for a dollar for each day since our independence. Thank you!

Ronald Marenda made donations to honor Bob & Carolyn Hoffman's 50th wedding anniversary.

The PEP Pioneers made donations in memory of dear departed PEP Pioneers Edna Mae Carol, Melvin Melvoid, Shirley Norte, Harold Winslow , Alicia Carper, Marilynn Eden, Evelyn Gould, Jerry Matsumoto, Fred Burdette, Andy Watson, Bob Spangler, Myrel Dye, Marvin Denny and Alvin Umphfres. We join in offering our sympathies to the families and friends of these PEP Pioneers.

M.F. Bowen is the Research Administrator of the Tobacco-Related Disease Research Program (TDRP) at the University of California. *She currently oversees both the Cancer and Pulmonary portfolios for the program. She is the author of 30 peer-reviewed scientific publications. The article below appeared in "Burning Issues", the April 2004 TRDRP newsletter, Volume 6(3): page 12. We thank her for allow ing us to republish this scholarly paper.*

Pulling the Plug on Research Funding: What it Means to the Victims of Chronic Obstructive Pulmonary Disease

M. F. Bowen, Ph.D.

While lung cancer rates have declined in California since 1988 (1), **mortality due to chronic obstructive pulmonary disease (COPD) is on the rise, with deaths in women and African Americans of both sexes responsible for most of the increase (2).** COPD is not going away: Smoking rates in 18-24 year-olds are on the upswing in California (3) as well as across the country (4). Given the difficulty of quitting, many of these smokers will be the COPD patients of the future. Furthermore, management of chronic diseases such as COPD is at a crisis point (5). In light of this ominous trend, **the decision to cut research funding for tobacco-related disease could very well presage a public health catastrophe.** Indeed, the demands on medical services for this disease would seem to call for increased, rather than decreased, funding.

As detailed elsewhere (6,7), research funds that are more urgently needed for COPD research are being misdirected to the California Cancer Registry and the Environmental Investigations Branch. Given this scenario, it behooves us to ponder the impact that TRDRP's plummeting research dollars will have on those individuals who suffer the most: Californians who will become sick and die as a result of their addition to nicotine. This article describes the issues surrounding chronic obstructive pulmonary disease (COPD) and why **cutting research funding at this point is short-sighted at best and calamitous at worst.**

The Breath-Taking Statistics

The percent change in the age-adjusted mortality rate for COPD increased 163% between 1965 and 1998 in the US. In this regard COPD stands in stark contrast to all other causes of death, including cardiovascular disease, stroke and cancer, all of which have undergone either a decline in mortality rate or maintained a steady rate during that time period. (8) In the US, approximately 119,000 adults died from COPD in 2000 (9). Mortality rates have increased in women, and African Americans of both sexes. It is now the 4th leading cause of death in the US (after cardiovascular disease, stroke and cancer) and is expected to move to third place by 2020 (9). The situation in California mirrors this national trend (2). **COPD cost the US $32.1 billion in 2002 –$18 billion of which was spent on direct health**

care costs (10). Globally, COPD currently ranks 12th as a disease burden; by 2020 it is projected to rank 5th (11). What is driving this disturbing trend?

Smoking Takes Your Breath Away

Smoking is the primary risk factor for COPD, accounting for almost 90% of the COPD cases in the US (10). A smoker is ten times more likely to die of COPD than a non-smoker (10). Because COPD does not usually manifest until middle age, the stunning increase in disease prevalence and mortality in the US clearly represents an accumulated disease burden resulting from pastsmoking prevalence, particularly in women (12).

Approximately 1.1 billion people in the world smoke; this is expected to increase to 1.6 billion by 2025 (13). The successful marketing of cigarettes to developing countries by the tobacco industry and changes in age demographics are fueling the increase in COPD throughout the developing world. It is not surprising that COPD is expected to undergo such a dramatic world-wide rise over the next 2 decades.

Might we expect Big Tobacco to stop selling cigarettes in light of this dismaying epidemic? Don't hold your breath! **From 1998 to 2001, Big Tobacco advertising and promotional expenditures within the US increased 66.6% from $6.73 billion to $11.22 billion; this included 3.9 billion cigarettes that were given away for free in 2001 alone (14).** ***In 1998 the combined global revenues of Philip Morris, Japan Tobacco, and British American Tobacco was in excess of $88 bilion. Philip Morris International's revenues increased 226% between 1989 and 1999 (15).*** This marketing tsunami and global profiteering has not gone unnoticed by Wall Street: Tobacco stocks still offer an excellent return on investment and are recommended "buys" (16,17). Unfortunately, what is being "bought" in this case is the health of the public.

Waiting to Exhale

What is COPD? It is a pathological lung condition characterized by irreversible airflow limitation. COPD sufferers experience shortness of breath, cough and excess sputum. Pockets of dead air accumulate in the dysfunctional air spaces and expiration becomes difficult. Breathlessness may initially be evident only upon exertion but later may be present continuously. The disease is believed to be caused by an abnormally prolonged inflammatory response of the lungs to airborne irritants, which ultimately results in destruction of lung tissue, enlargement of the air spaces and loss of elastic recoil. Airway narrowing due to fibrosis contributes to respiratory impairment in the later stages of the disease. Disability and, in some cases, complete immobility results. COPD patients with advanced disease often require continuous oxygen supplementation and frequent hospitalization. The damage to lung integrity and function caused by smoking cannot be undone. Nonetheless, smoking cessation ameliorates the inflammatory process, decreases cough and sputum production and decelerates the decline in lung function. **The take-home message here is that *it is never too late to quit:* COPD patients should make every effort to do so and should be given the support and guidance they need to make their efforts successful.**

The primary pharmacologic treatments for COPD include bronchodilators and glucocorticosteroids. **Pulmonary rehabilitation and oxygen therapy are also often prescribed.** Lung volume reduction surgery is recommended only in carefully selected patients. Lung transplantation is a treatment of last resort and is limited by a shortage of donor organs and cost. All of these treatments merely ameliorate the symptoms. There is currently no cure for COPD.

Waiting With Bated Breath - For a Diagnosis

Astonishingly, COPD remains largely unrecognized by the public and is notoriously underdiagnosed by the medical community. **It is estimated that over 24 million people in the US have COPD; yet over half of those afflicted do not realize it (9).** There are several reasons for this. The symptoms - cough, sputum, shortness of breath – are often erroneously thought to be the inevitable consequences of aging. Sufferers don't go to their doctor until breathing is severely impaired. Symptoms are often mistaken for those of asthma or heart disease. **Over 75% of cases see a primary care physician; however few such physicians perform spirometry, which is currently the only way to accurately diagnose the condition** (18,19). Thus less than 50% of estimated cases are accurately diagnosed.

Research Funding: Gasping for Breath

COPD has the dubious distinction of being the most under-funded of all the major diseases in the US. Dollars spent on research per COPD death is a mere $508 (20). This stands in stark contrast to 2001 funding levels of HIV/AIDS ($ 34,000), breast cancer ($9,000), and prostate cancer ($3500). Even lung cancer, another sadly neglected public health issue, is better funded than COPD: $900 per death was spent on lung cancer research in the US in 2001(21).

Like lung cancer, COPD is a stigmatized disease. But whereas lung cancer victims succumb to their disease relatively quickly, COPD patients live a relatively long time, albeit in a debilitated and disabled state. **Victims of COPD have begun the long and arduous process of uniting for their common cause and making their voices heard to change health care policy, educate the public, and encourage research to prevent and assuage the ravages of COPD.**

A Breath of Fresh Air A group of health care professionals, researchers, and patient activists are sounding the alarm about the impact of COPD on current and future public health. **The US COPD Coalition** is a group of professional, government, academic and patient organizations working to reduce the prevalence and mortality of COPD. The coalition organized the first National COPD Conference held on Nov. 14-15, 2003 in Arlington, VA. Issues discussed ranged from causes, epidemiology, pathogenesis, diagnosis and treatment to health care policy and economics. This was an historic moment for COPD, its victims, and the health care professionals who care for them. It was clear from the discussion at this meeting that research is urgently needed in many areas including epidemiology, health care policy, chronic disease management, pathogenesis, diagnosis, education, translation and treatment. For example, the **pathogenesis of COPD is still largely a mystery.** Understanding the cellular and molecular processes underlying lung inflammation and destruction will enable the development of better treatments and, eventually, prevention or curative

measures such as lung regeneration. Given the diagnostic problems that have plagued the field for so long, epidemiological studies are needed to assess the true extent of the problem, particularly in California where access to care, ethnic and cultural issues complicate the picture. Health policy research on the costs and benefits of treating this chronic disease is urgently needed. Finally, it is absolutely necessary to continue to investigate, scrutinize and research the tobacco industry – its tactics and the economic toll it exacts on this country and throughout the world. Such research tells the industry that we're watching every breath they take and every move they make. Only by knowing our enemy can we effectively combat the gargantuan marketing, political and legal juggernaut that is Big Tobacco.

COPD has taken a toll on public health and that toll is increasing day by day. It is time to say "Enough!" Through funding, research, activism, and dissemination we can make inroads into the prevention and treatment of this disease. It seems at times that smoking has devolved in the public's mind into a mere faux pas or a minor act of rebellion. Smoking is much more than that. Smoking is increasing the odds of living out the last years of life in a state of debilitation, infirmity and misery. **Smoking isn't worth that sacrifice.**

When we think about Prop. 99 and how best to allocate its funds in times of fiscal crisis, let's think twice and consider the future medical and public health implications of our decisions. COPD is not only physiologically and emotionally devastating to its victims but, as a long-term chronic condition, fiscally devastating to patients, their families and the California economy. Raiding the Research Account and using these funds for anything other than tobacco-related disease research is misguided at best. Think twice. It's not alright.

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Recommendations for Future Research

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Initiatives

- GOLD – Global Initiative for Chronic Obstructive Lung Disease. Objective: To increase awareness of COPD among health professionals, health authorities and the public; improve diagnosis, management and prevention; stimulate research. www.goldcopd.com

- NLHEP - National Lung Health Education Program: A nationwide education program aimed at physicians, patients and the public. Objective: to diagnose and treat patients in the early stages of COPD so that progression can be slowed or stopped. www.NLHEP.org

New Journals

- *Emphysema/COPD: The Journal of Patient-Centered Care*
  http://www.l i fethreat.org/ journal.htm
- *COPD: Journal of Chronic Obstructive Pulmonary Disease*
  http://www.dekker.com/servlet/product/producti d/COPD

Patient Resources

- Petty, TL and Doherty, DE. 2003. Save Your Breath, America! Prevent Emphysema Now! Information on who may be developing emphysema or chronic bronchitis. National Lung Health Education Program, Denver, CO. URL: www.NLHEP.org.
- Schacter N. 2003. Life and Breath. 336 pp. Broadway Books, New York.
- The Pulmonary Research & Education Foundation. Box 1133 Lomita, California 90717-5133. Fax/Tel: (310) 539 – 8390. URL: www.perf2ndwind.org

Acknowledgements –

The author thanks Mary Burns, RN, BS, Executive Vice President of the Pulmonary Education and Research Foundation and Thomas L. Petty, M.D., MACP, Master FCCP, Chairman Emeritus NLHEP and Professor of Medicine, University of Colorado Health Science Center Denver, for their helpful comments, suggestions, and encouragement.

The author acknowledges Terry McMillan author of "*Waiting to Exhale"* (Viking Press, 1992) and Sting "*Every Breath You Take"* ("Synchronicity", The Police, 1983).

Whew! What a lot of information! We debated on whether we should leave in all the references typical of a scholarly article but felt it might be of interest to some of you. We hope this w ill impress you w ith the needs of the pulmonary patient (as if you didn't already know !). Won't you w ill urge your Washington representatives to join **Senator Crapo's COPD Caucus?** This Caucus not only w rote a strong letter of support urging Medicare to finance Pulmonary Rehab, but also w rote another to NIH (National Institute of Health) urging more research on pulmonary disease. Copies of both were lost in our "August Crash" but need to be mentioned as something positive coming out of Washington. Support these representatives w ho are supporting you!

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The Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center will present ***COPD/Alpha-1 Education Day*** ***Saturday October 2nd.*** Join us for this outstanding **free** educational event at the Hilton Carson Plaza Hotel in Carson, California, right off the 405 San Diego Freeway. **Special rates are available at the hotel if you wish to spend the night. Physicians and other health care providers receive free CEU's and CMEs for the lectures attended including one on end of life issues,** *Free box lunches and coffee breaks will be provided as you cruise the many exhibits.* **Reservations are absolutely necessary.** ***To make them, call Candi Hacker toll free a t(866) 229-2768.***

COPD/ALPHA1 EDUCATION DAY SCHEDULE

8:30AM to	9:15AM	REGISTRATION, BREAKFAST,AND EXHIBITOR D ISPLAY
9:15AM to	9:30AM	INTRODUCTION, WELCOMEAND OPENING REMARKS BY: R. CASABURI

TRACK A PROFESSIONAL				TRACK B PATIENTS			
			SPEAKER				**SPEAKER**
9:45 AM	to	10:15 AM	**J. Vintch**	9:45 AM	to	10:15 AM	**B. Fallat**
			The GOLD STANDARD for Treatment of COPD				**Alpha-1 Genetics and Diagnosis**
10:15 AM	to	10:45 AM	**D. Sue**	10:15AM	to	10:45AM	**R. Casaburi**
			Targeting COPD Exacerbations				**The Rise of Pulmonary Rehabilitation**
10:45 AM	to	11:15 AM	**B. Fallat**	10:45AM	to	11:15AM	**J. Vintch**
			Alpha-1 Genetics and Diagnosis				**The GOLD STANDARD for Treatment of COPD**
11:15AM	to	12:45 PM	**LUNCH AND EXHIBITOR DISPLAYS**				
12:45 PM	to	1:15 PM	**P. Selecky**	12:45 PM	to	1:15 PM	**K. Landis**
			W hat Happens in Bed: Sleep and Sexuality				**End of Life Concerns: Lessons from Cruzan and W endland**
1:15 PM	to	1:45 PM	**R. Casaburi**	1:15 PM	to	1:45 PM	**D. Sue**
			The Rise of Pulmonary Rehabilitation				**Targeting COPD Exacerbations**
1:45 PM	to	2:15 PM	**B. Tiep**	1:45 PM	to	2:15 PM	**P. Selecky**
			NewDevelopments in Long Term Oxygen Therapy				**W hat Happens in Bed: Sleep and Sexuality**
2:15 PM	to	2:30 PM	**BREAK FOR ALL PARTICIPANTS**				
2:30 PM	to	3:00 PM	**R. Casaburi**	2:30 PM	to	3:00 PM	**T. Hodges**
			Emerging Therapies for COPD				**Surgical Options for the PulmonaryPatient**
3:00 PM	to	3:30 PM	**K. Landis**	3:00 PM	to	3:30 PM	**B. Tiep**
			End of Life Concerns: Lessons from Cruzan and W endland				**NewDevelopments in Long Term Oxygen Therapy**
3:30 PM	to	4:00 PM	**T. Hodges**	3:30 PM	to	4:00 PM	**R. Casaburi**
			Surgical Options for the PulmonaryPatient				**Emerging Therapies for COPD**
4:00 PM	to	4:15 PM	***Rehabilitation Clinical Trials Center- R. Casaburi***				
4:15 PM	to	4:30 PM	***Alpha-1 Foundation - E. Schuck***				
4:30 PM	to	4:45 PM	***Alpha-1 Association - M. O˙Day***				
4:45 PM	to	5:00 PM	***NECA - B. Rogers***				
5:00 PM	to	5:05 PM	***PERF- M. Burns***				
5:05 PM	to	5:10 PM	***CSPR - J. Barnett***				
5:10 PM	to	5:15 PM	***Closing Remarks***				

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Senior Moderator

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September 2004

Dear Friends:

BETTER WATCH THE BIRDS THAN THE NEWS!

Today, I find the television new s most discouraging and disgusting at times. Never any good new s. It is alw ays tragedy, trauma, domestic mayhem, or natural disasters. Seems like never any good new s. I long for the old days, remembered by some, w hen World War II commentator Gabriel Heater began his broadcasts w ith, “There is good new s today.” Would it w ere true now . How often do you see a new scast interrupted w ith CBS, NBC, ABC/CNN new s break, “Good new s for America”?

By contrast, I am alw ays entertained by w atching the birds feed on the patio. I notice their pecking order, the species of birds that arrive and at w hat time. In fact, the w hole “micro menagerie” is fascinating. It begins w ith the sparrow s, chickadees, and a scattering of red finches. Then an occasional mourning dove and, rarely, a woodpecker. From time to time a field mouse will poke his head out of a brick sanctuary surrounding a bright yellow flow er bed. You get to see the birds arrive at certain times, feed w ith abandon and then scatter once again, only to return. They are alw ays entertaining and relaxing.

Today, the new s is painfully draw n to horror and suffering, a sort of penance in life, I guess. I personally limit myself to about one hour of this repetitive and unsettling commentary about the decadent trends that have beset mankind.

But the birds are an uplifting alternative. They are reliable, entertaining, and just plain fun.

Forget the new s– it’s for the birds!

I’ll be in touch next month.

Your friend,

Thomas L. Petty, M.D.
Professor of Medicine
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September 2004

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